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ABSTRACT

The paper examines the assumptions, historical developments of the federal service delivery system for developmentally disabled persons. Services for the disabled are seen to have evolved from criteria oriented programs to entitlements with accompanying guarantees of due process. Major federal programs are traced from the 1918 Vocational Rehabilitation Act for disabled veterans to the passage of P.L. 95-602, the Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978. Fiscal year 1979 appropriations levels for 14 major federal programs are listed, and organizational patterns of four federal programs are illustrated. Trends in deinstitutionalization, normalization, and the developmental model are considered. Inadequacies of proposed national health insurance plans are pointed out, and alternative plans to provide long term care for chronically disabled persons are described. (CL)

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Volume Eight

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AN ORIENTATION TO THE EXISTING SYSTEM OF PUBLIC FINANCING PROGRAMS CURRENTLY UTILIZED IN PROVIDING SERVICES TO PERSONS WITH DEVELOPMENTAL DISABILITIES

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AN OVERVIEW OF THE PUBLIC SERVICE
DELIVERY SYSTEM FOR PERSONS WITH
DEVELOPMENTAL DISABILITIES

An examination of the assumptions, historical developments, and organizational patterns of the federal service delivery system.

- Target: Comprehensive and Coordinated Human Services Delivery System: A Conceptual Perspective

The professed objective of public policy advocates for the disabled is the creation of a comprehensive and coordinated human services delivery system, appropriate for individual needs and significantly involving the private sector. Such a system may be conceptualized in the following manner:

Housing Education Transportation Day Activities Income Medical Services Etc.	State DD Council and Agency	Section 504 Enforcement Protection and Advocacy System	UCPA Advocacy and Direct Service Roles Based on Individual Needs

- The Public Responsibility Concept

UCPA has been advocating for several years the placement of a tax base under important generic services for persons with disabilities. Government has slowly responded and has assumed increasing responsibility for the disabled. This has occurred because the problems are too severe and the necessary resources too inadequate for private charity to solve alone. Public responsibility is being accepted slowly, as demonstrated in the education area. But responsibility for the disabled today is an idea, not a reality.

- The Idea Of An Entitlement

When the public sector first initiated programs for the disabled, they were designated service programs for selected groups of individuals under certain specified conditions. Today, more and more programs are becoming entitlements. Disabled persons are entitled to service and they do not have to meet certain conditions. They are entitled to public education. They are entitled to appropriate treatment. They are entitled to due process and equal treatment under the law.

Frank Laski defines entitlement to service as existing when two conditions are met: (1) There exists a definable duty on the part of ascertainable service providers to give service to a particular person (or persons in general); (2) The persons who are the beneficiaries of the duty have a legal remedy which they can use to enforce performance of the duty, or collect damages for failure to perform. (3) Without both conditions, the duty and the capacity to enforce the duty, there is no entitlement. A developmentally disabled person may demand the service, his family may buy the service if they can afford it, they may claim a moral obligation exists to provide the service. But without the two conditions - the duty and the capacity to enforce the duty - there is no entitlement.

Yet the issue of entitlement has difficulties for voluntary organizations. UCPA believes in public responsibility for persons with disabilities. Yet we also recognize that a system has evolved with a government program with a large bureaucracy feeding off it. The question of social need frequently is a matter between the government and a recipient. The recipient has rights. The government has obligations. And the lawyers argue the fine points. The people just pay the bills. And voluntary agencies are losing much of the responsibility and with it some of the concern and feeling. And so we have resorted to advocacy roles. We ask the government to pay for one thing and they give us something else.

- Due Process

Due process of law, once a term understood by lawyers only, is now becoming part of our everyday vocabulary. The term has a special meaning to parents of disabled children and to persons with disabilities. It is a legal way of saying that every person is treated fairly and is not denied his rights as a citizen. Examples include:

1) Education. Title VI, the Education for the Handicapped Act, requires state and local school districts to provide procedures for insuring that handicapped children and their parents or guardians are guaranteed procedural safeguards in decisions regarding identification, evaluation, and educational placement of handicapped children.

2) Social Security. The Supplemental Security Income Program establishes detailed criteria permitting the applicant and recipient to question and challenge decisions regarding his eligibility, payment levels, etc.

- Historical Development Of Major Federal Programs For Persons With Developmental Disabilities

1)a) 1918, Vocational Rehabilitation Act for disabled veterans.

b) 1920, "National Civilian Vocational Rehabilitation Act of 1920."

2) 1933, "Federal Emergency Relief Act;" cash payments for poor individuals.

3) 1935, "Social Security Act."

a) Cash payments to families with dependent children, old age assistance, and survivors assistance.

b) Established the Maternal and Child Health and Crippled Children Services Programs.

4) 1950, Social Security Amendments; established a separate federal grant-in aid program to "permanently and totally disabled" adults.

5) 1957, Social Security Amendments; Disability Insurance program established.

6) 1962, Social Security Act Amendments; Social Services for public assistance recipients authorized.

7) 1963, "Maternal and Child Health And Mental Retardation Planning Amendments of 1963." P.L. 88-156, October 24, 1963, targeted resources on the mentally retarded and established a state planning mechanism for persons with mental retardation.

8) 1963, "Mental Retardation Facilities And Community Mental Health Centers Construction Act of 1963." P.L. 88-164, October 31, 1963, established community mental health centers and authorized the construction of mental retardation centers and university affiliated facilities for the mentally retarded.

9) 1963, "Vocational Education Act of 1963." P.L. 88-210.

10) 1964, "Urban Mass Transportation Act of 1964." P.L. 88-365 established federal grants for mass transit.

11) 1965, "Elementary And Secondary Education Act of 1965." P.L. 89-10, April 11, 1965.

12) 1965, "Social Security Amendments of 1965." P.L. 89-97, July 30, 1965, established the Medicaid and Medicare programs.

13) 1965, "Elementary and Secondary Education Amendments." P.L. 89-313, November 1, 1965, authorized federal funds to state owned and operated schools for the handicapped (institutions).

14) 1966, "Comprehensive Health Planning And Public Health Services Amendments of 1966." P.L. 89-749, November 3, 1966, established health planning agencies in the states.

15) 1967, "Mental Retardation Amendments of 1967." P.L. 90-170, December 4, 1967, authorized partial payment of the cost of professional and technical personnel in mental retardation facilities.

16) 1968, "Architectural Barriers Act of 1968." P.L. 90-480, August 12, 1968, required federally funded buildings to be accessible to the disabled.

17) 1968, "Handicapped Children's Early Education Assistance Act;" P.L. 90-538, September 30, 1968, authorized federal grants to the states for educating handicapped children.

18) 1968, "Vocational Education Amendments of 1968." P.L. 90-576, October 16, 1968, required 10% state setaside for the handicapped under the Voc Ed program.

October, 1968: UCPA Establishes A Washington Office

19) 1970, "Developmental Disabilities Services and Facilities Construction Act of 1970." P.L. 91-517, October 30, 1970, drastically amended the old mental retardation laws. Cerebral palsy was specifically listed as a developmental disability and state planning councils were firmly established.

20) 1971, "Social Security Amendments." P.L. 92-223, December 28, 1971, established the Medicaid Intermediate Care Facility for the Mentally Retarded (and other developmentally disabled) program.

21) 1972, "State and Local Fiscal Assistance Act." P.L. 95-512, October 20, 1972, established the Revenue Sharing program and placed a $2.5 billion ceiling on the Title XX program.

22) 1972, "Social Security And Welfare Reform Amendments of 1972." P.L. 92-602, October 30, 1972, established the Supplemental Security Income (SSI) program.

23) 1973, "Federal Aid Highway Act of 1973." P.L. 93-87, August 13, 1973, required federal mass transit projects to be accessible to the handicapped.

24) 1973, "Rehabilitation Act of 1973." P.L. 93-112, September 26, 1973, revised the VR program to include special emphasis on the severely handicapped, established the Architectural and Transportation Barriers Compliance Board, and authorized Title V civil rights protections, including Section 504 nondiscrimination protections.

25) 1973, "Comprehensive Employment and Training Act of 1973." P.L. 93-203, December 28, 1973, established a consolidated manpower training program.

26) 1974, "Housing And Community Development Act of 1974." P.L. 93-383, August 22, 1974, for the first time targeted federal housing programs for the disabled. Of special note are Section 202 construction and Section 8 rent subsidies programs.

27) 1975, "National Health Planning And Resources Development Act of 1974." P.L. 93-641, January 4, 1975, strengthened health planning agencies.

28) 1975, "Social Services Amendments of 1974." P.L. 93-647, January 4, 1975, consolidated Social Services programs into a new Title XX.

29) 1975, "Developmental Disabilities Assistance and Bill of Rights Act." P.L. 94-103, October 4, 1975, established Protection And Advocacy Systems for the developmentally disabled in every state.

30) 1975, "Education For All Handicapped Children Act of 1975." P.L. 94-142, November 29, 1975, declared that every handicapped child is entitled to a "free, appropriate, public education."

31) 1978, "Comprehensive Employment And Training Act Amendments of 1978." P.L. 95-524, October 27, 1978, specifically included the handicapped within the definition of "economically disadvantaged" and targeted special national attention to the handicapped.

32) 1978, "Housing And Community Development Amendments of 1978." P.L. 95-557, October 31, 1978, established a new Congregate Housing Services Program.

33) 1978, "Rehabilitation, Comprehensive Services, And Developmental Disabilities Amendments of 1978." P.L. 95-602, November 6, 1978, altered the categorical definition of developmental disability to a functionally based

one; strengthened consumer composition on State councils; targeted DD funds to the national service priorities of community living arrangements, case management, child development, and vocational/social-developmental services; established the Comprehensive Services for Independent Living Program, established the National Institute of Handicapped Research, and authorized community services employment pilot programs.

- Scope and Significance Of Major Federal Programs For Persons With Developmental Disabilities

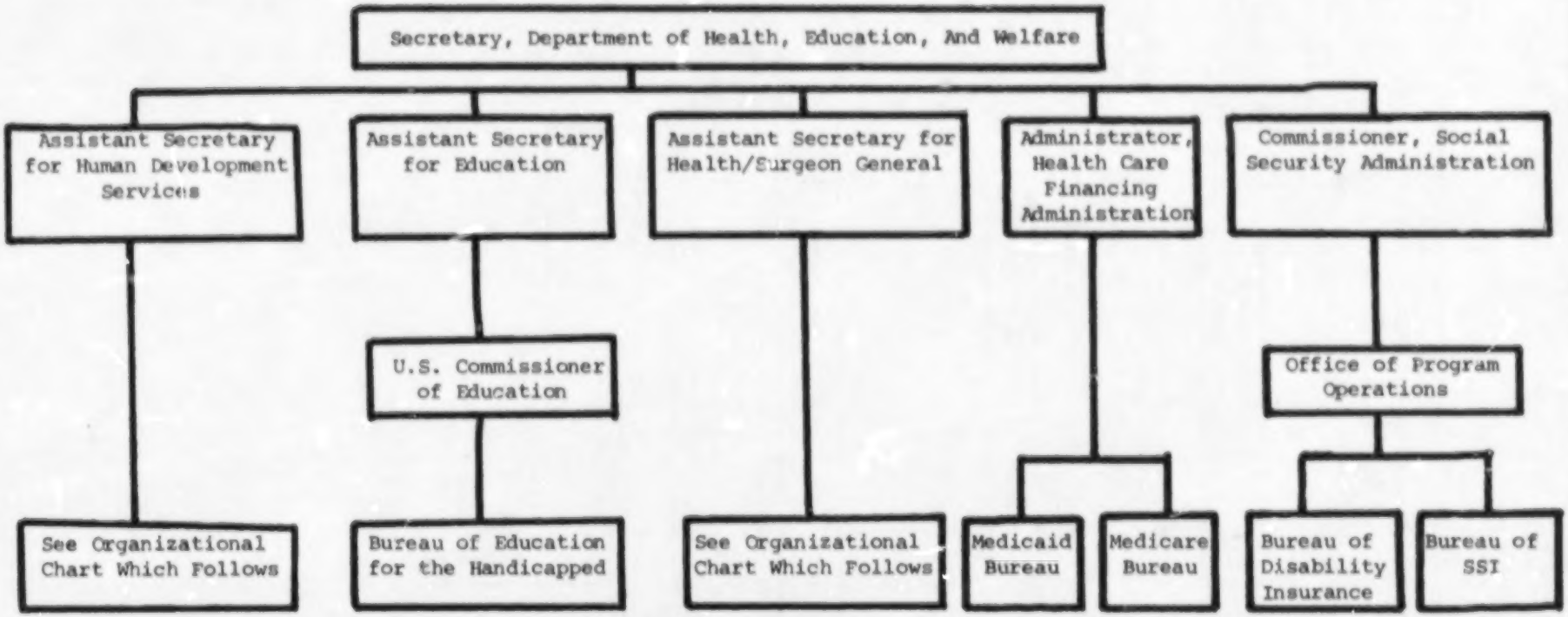
Program (* not all benefits go to the disabled)	Fiscal Year 1979 Appropriation	
1) Supplemental Security Income*	$ 5.940	billion
2) Social Security Disability Insurance	14.393	billion
3) Medicaid*	11.804	billion
4) Medicare*	7.760	billion
5) Title XX Social Services*	2.900	billion
6) Developmental Disabilities		
a) State Grants	35.0	million
b) Protection And Advocacy Systems	3.8	million
c) National Projects	13.767	million
d) University Affiliates Facilities	6.5	million
7) Vocational Rehabilitation		
a) State Grants	817.5	million
b) Innovation And Expansion	18.0	million
c) Service Projects	32.0	million
d) Research	31.5	million
e) Training	30.5	million
8) Comprehensive Services For Independent Living	2.0	million
9) Education For All Handicapped Children		
a) P.L. 94-142 State Grants	804.0	million
b) Pre-School Incentive Grants	17.5	million
c) Severely Handicapped Projects	5.0	million
d) Early Childhood Projects	22.0	million
e) P.L. 89-313 State Grants	130.0	million
f) Vocational Education 10% setaside for the handicapped	57.1	million
g) Head Start 10% enrollment requirement for the handicapped	62.0	million
10) Department of Housing And Urban Development		
*a) Section 8 rent subsidies	25.367	billion
*b) Section 202 construction loans	800	million

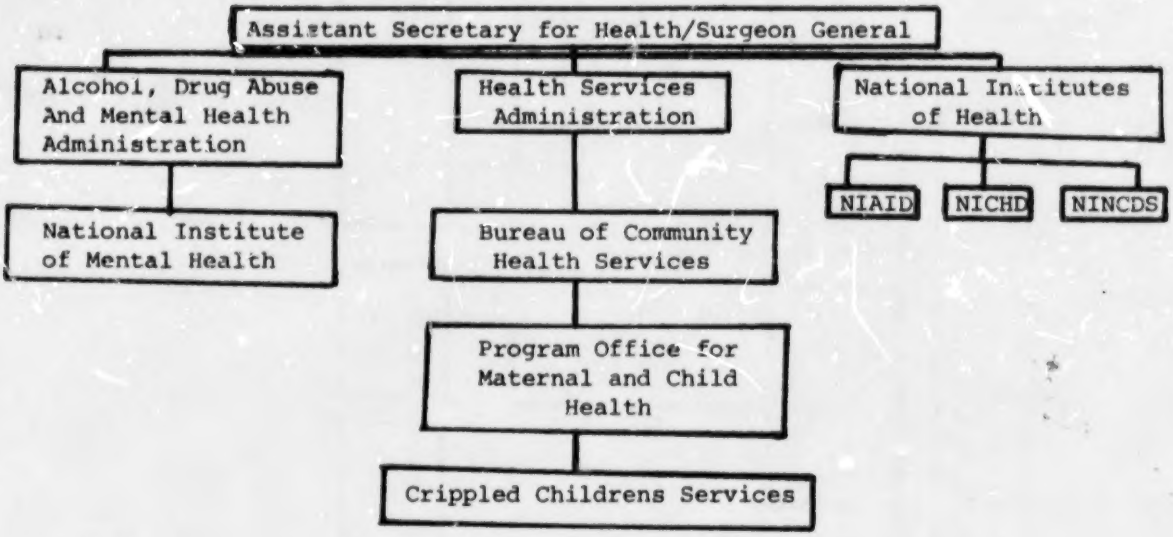
*c) Section 106(b) seed money loans for Section 202 sponsors	5.750	million
*d) Congregate Housing Services Program	10.0	million
11) *Comprehensive Employment And Training Act	7.060	billion
12) Urban Mass Transportation Administration, Department of Transportation		
*a) Urban Discretionary Grants	1.250	billion
*b) Urban Formula Grants	1.403	billion
*c) Nonurban Formula Grants	56.5	million
13) National Institutes Of Health		
*a) National Institute of Neurological and Communicative Disorders And Stroke (NINCDS)	212.4	million
*b) National Institute of Child Health and Human Development	195.1	million
*c) National Institute of Allergy And Infectious Diseases (NIAID)	191.3	million
14) Maternal And Child Health/Crippled Childrens Programs		
*a) MCH State Grants	304.4	million
*b) MCH/CCS Research and Training	32.2	million
c) CCS State Grants	76.0	million

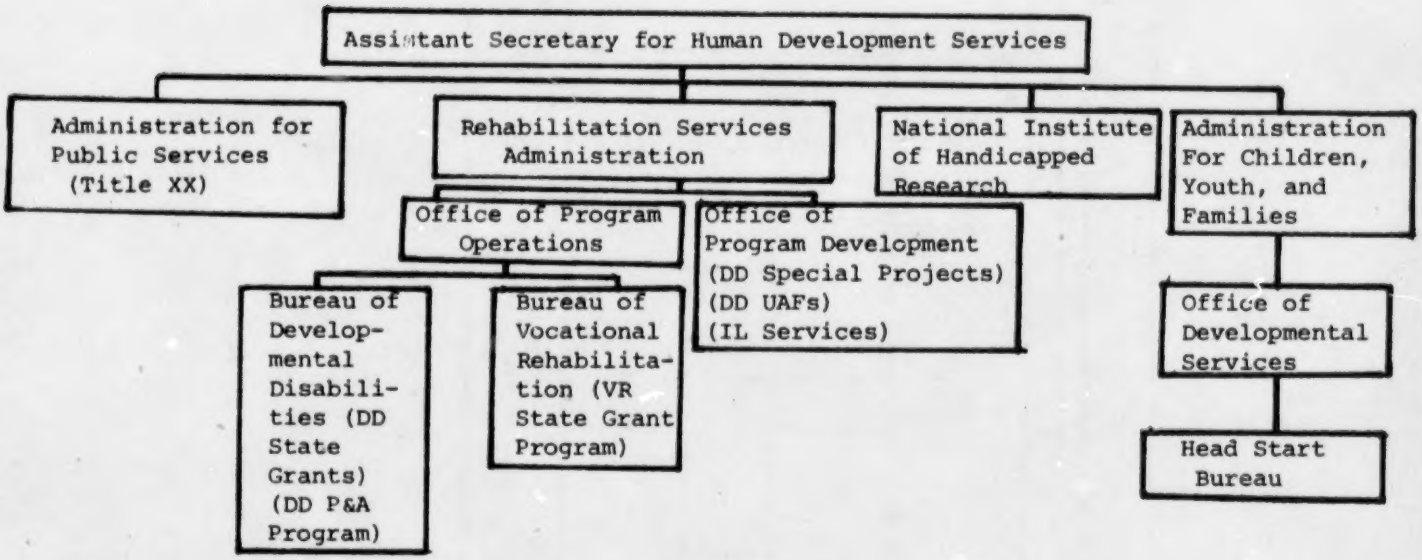
- Organizational Structure Of Major Federal Programs For Persons With Developmental Disabilities*

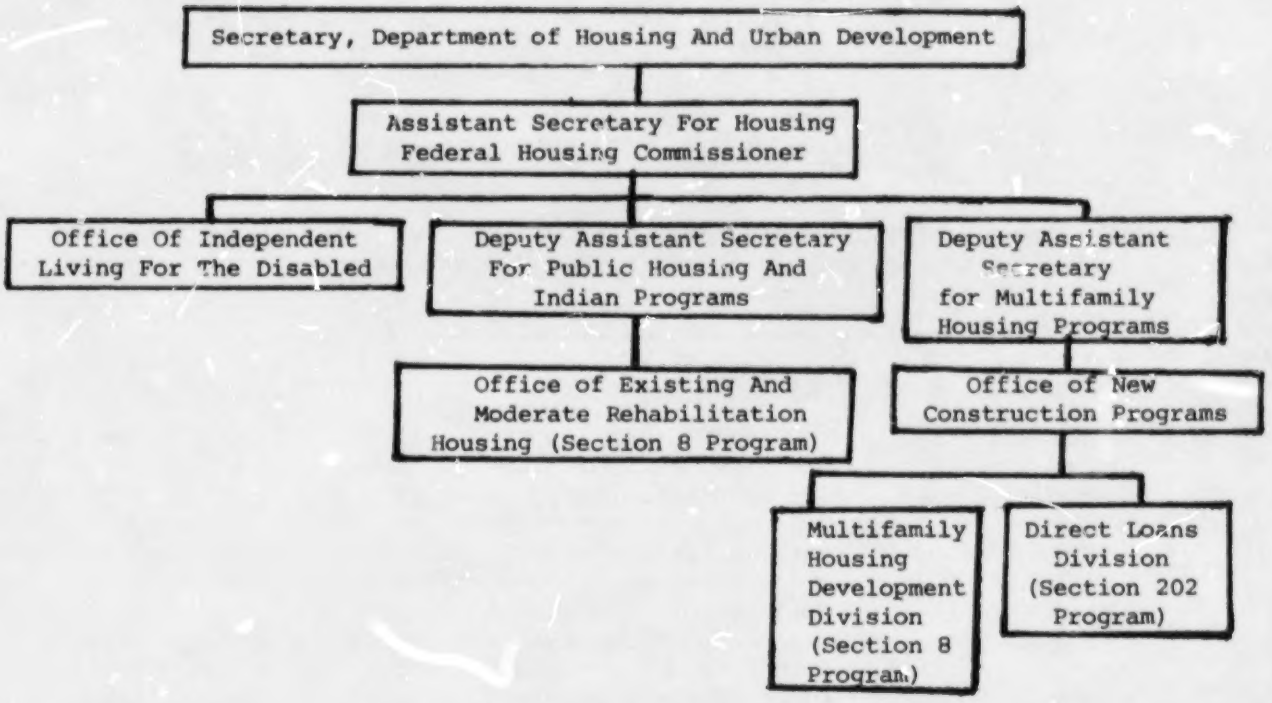
*It should be noted that legislation (H.R. 2444 and S. 210) has passed both the House and Senate establishing a Department of Education. The bills are awaiting resolution by a Congressional Conference Committee. Under both bills, all programs authorized under the "Rehabilitation Act of 1973" would be transferred to the new Department of Education; the Bureau of Education for the Handicapped, Rehabilitation Services Administration, and National Institute of Handicapped Research would report to a new Assistant Secretary for Special Education and Rehabilitation Services. The Developmental Disabilities program would be retained in the new Department of Health and Human Development. This organizational structure is based on what exists today.

Why should advocates for the disabled be concerned with organizational configurations? In general, the larger the population and the more heterogeneous that population, the less likely that individual needs will be met. Aggregate policy development tends to treat everyone identically and does not attempt to meet individual needs. Thus the need for a separate organizational response to particular needs. Secondarily, the higher an office is in the bureaucratic structure, the greater its influence with leading policy makers, the greater the possibility of having its concerns responded to, and the greater resources it will have. If one desires greater attention devoted to the disabled accompanied by higher appropriations, one should seek a higher administrative placement of these offices.

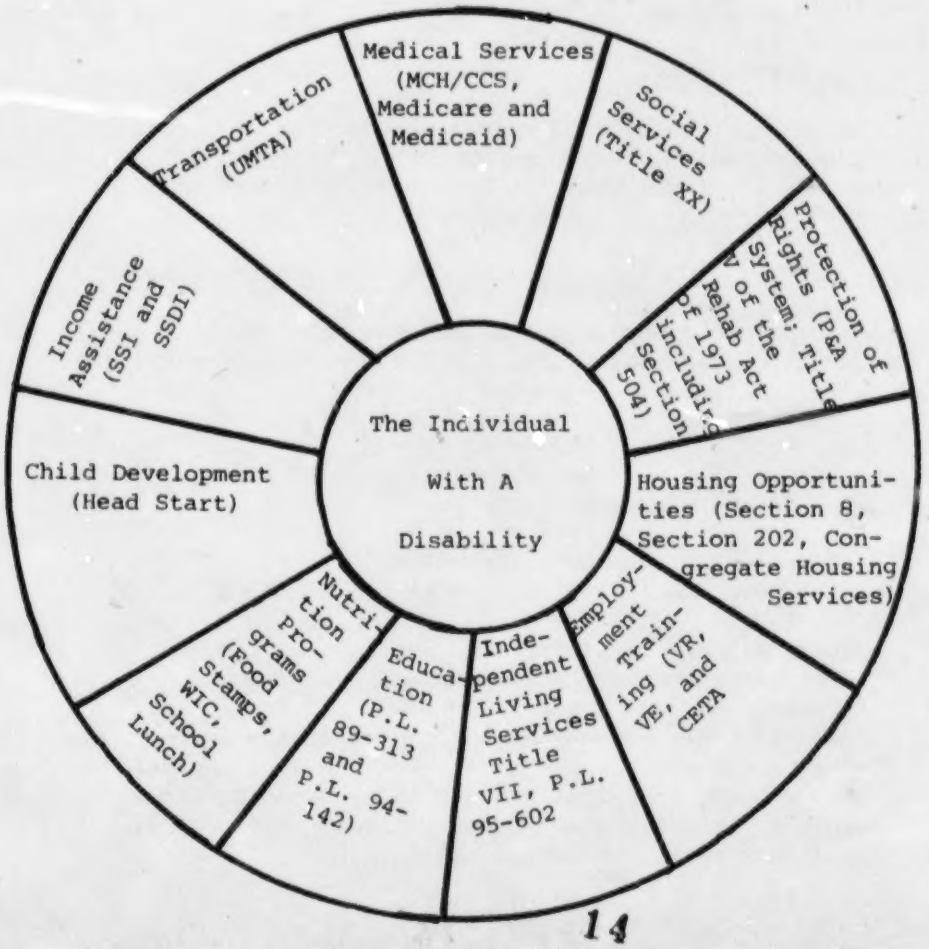

Secretary, Department of Health, Education, And Welfare
Assistant Secretary for Human Development Services
Assistant Secretary for Education
Assistant Secretary for Health/Surgeon General
Administrator, Health Care Financing Administration
Commissioner, Social Security Administration
U.S. Commissioner of Education
Office of Program Operations
See Organizational Chart Which Follows
Bureau of Education for the Handicapped
See Organizational Chart Which Follows
Medicaid Bureau
Medicare Bureau
Bureau of Disability Insurance
Bureau of SSI


Assistant Secretary for Health/Surgeon General
Alcohol, Drug Abuse And Mental Health Administration
Health Services Administration
National Institutes of Health
NIAID
NICHD
NINCDS
National Institute of Mental Health
Bureau of Community Health Services
Program Office for Maternal and Child Health
Crippled Childrens Services


Assistant Secretary for Human Development Services
Administration for Public Services (Title XX)
Rehabilitation Services Administration
National Institute of Handicapped Research
Administration For Children, Youth, and Families
Office of Program Operations
Office of Program Development (DD Special Projects) (DD UAFs) (IL Services)
Bureau of Developmental Disabilities (DD State Grants) (DD P&A Program)
Bureau of Vocational Rehabilitation (VR State Grant Program)
Office of Developmental Services
Head Start Bureau


Secretary, Department of Housing And Urban Development
Assistant Secretary For Housing Federal Housing Commissioner
Office Of Independent Living For The Disabled
Deputy Assistant Secretary For Public Housing And Indian Programs
Deputy Assistant Secretary for Multifamily Housing Programs
Office of Existing And Moderate Rehabilitation Housing (Section 8 Program)
Office of New Construction Programs
Multifamily Housing Development Division (Section 8 Program)
Direct Loans Division (Section 202 Program)

- A Conceptualization Of The Major Federal Support Programs For The Disabled


The Individual With A Disability
Medical Services (MCH/CCS, Medicare and Medicaid)
Social Services (Title XX)
Protection of Rights (P&A System; Title V of the Rehab Act of 1973 including Section 504)
Housing Opportunities (Section 8, Section 202, Congregate Housing Services)
Employment Training (VR, VE, and CETA
Independent Living Services Title VII, P.L. 95-602
Education (P.L. 89-313 and P.L. 94-142)
Nutrition Programs (Food Stamps, WIC, School Lunch)
Child Development (Head Start)
Income Assistance (SSI and SSDI)
Transportation (UMTA)

TRENDS IN PUBLIC SERVICE DELIVERY FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

Deinstitutionalization, normalization, the developmental model, the individualization of service, and consumer direction and control are programmatic trends in the developmental disabilities area. Some of these have become public policy concerns.

- Deinstitutionalization

Section III of P.L. 94-103 (the Developmental Disabilities Act) mandated each state in receipt of federal DD funds to develop a plan designed to eliminate inappropriate placement in institutions of persons with developmental disabilities and to improve the quality of care and the state of surroundings of persons for whom institutional care is appropriate. The Act also required states to support the establishment of community programs as alternatives to institutionalization. Section 110 of P.L. 94-103 mandated that not less than 10 percent of a state's DD allotment in fiscal year 1976 be expended for the purpose of developing plans designed to eliminate inappropriate placement in institutions. For each succeeding fiscal year, not less than 30 percent of the state's allotment must be expended for this purpose.

Deinstitutionalization is a very broad category which includes three primary areas of attention: 1) prevention, reducing institutional intake by offering alternative types of placement; 2) reform, increasing the capabilities and independence of residents through highly skilled training; and 3) outreach, increasing community programs and homelike living arrangements and promoting public acceptance of the disabled as neighbors and employees.

Though the P.L. 95-602 DD amendments did not specifically continue the deinstitutionalization setaside, the four national service priorities reinforce and promote deinstitutionalization. Both HEW and HUD have stated policies to promote deinstitutionalization.

- Fiscal Constraints And The Importance Of Generic Programs

Generic programs may be defined as non-categorical programs which benefit a whole group or class (traditionally all persons below a certain arbitrary income level). In F.Y. 1979 the federal government allocated $82.1 billion to state and local government; $23 billion was for human resource programs.

Bob Gettings has outlined five implications for the disabled given this increasing reliance on generic programs:

(1) A tremendous growth in federal dollars to persons with developmental disabilities has occurred.

(2) The statutory authority for generic assistance programs generally have nothing to do with the programmatic goals for persons with developmental disabilities. A substantial amount of Washington representative time (such as the UCPA Governmental Activities Office) is devoted to eliminating instances in which the funding authority works at cross purposes with programmatic goals.

(3) Utilization of generic assistance programs require joint action by a number of state and/or local agencies to put funding packages together.

(4) Eligibility for one program frequently means eligibility for other programs; for example, the loss of SSI frequently results in the loss of Medicaid.

(5) Utilization of generic assistance programs result in strengthening state responsibility for plan development, service priorities, and eligibility parameters.

The Advisory Commission on Intergovernmental Relations (ACIR) in its May, 1979 report, Significant Features Of Fiscal Federalism, 1978-1979 Edition, estimates that federal aid as a per cent of state-local expenditures is declining from a peak of 26.7% in 1978 to 25.4% in 1979 to an expected 23.6% in 1980. Cited as causes for the projected decline are a drop in the funding of temporary economic stimulus programs, overall budget restraints as part of the effort to slow inflation, and the growing strains on the fiscal resources of the federal government.

The budget restraints are more likely to significantly affect categorical programs than generic programs. For example, during the next 3-5 years the Rehabilitation and Developmental Disabilities programs are likely to constitute only a miniscule portion of the dollars needed to substantially expand and improve independent living services to developmentally disabled persons. According to Gettings, if expansion is to take place a number of activities must occur:

(1) Generic service programs must be better utilized.

(2) Service expansion must be built upon existing service systems, not new ones.

(3) There is an overriding need for cooperative agreements to spell out areas of responsibilities by mutually reinforcing roles.

(4) Given the fiscal constraints and wide ranging service needs, priorities will have to be established.

(5) The initial key to success of any nationwide effort is action by state government.

• Philosophical Conflicts/Means Testing

UCPA and several of its sister agencies have been quite successful over the past several years in expanding the social services concept as authorized by Title XX of the Social Security Act. We have been successful in broadening eligibility for social services to persons in the median income category. With resource limitations, as exemplified by Title XX's annual $2.5 billion appropriations ceiling, efforts are being made to return the program to the very poor by limiting eligibility to recipients of financial assistance (SSI and AFDC). The administrators of public welfare agencies and the traditional social service workers employed by such agencies fear that the basic clientele of public welfare agencies - persons with low incomes - are receiving less and less attention. They fear that Title XX is evolving into another United Way, with private charitable organizations becoming the primary recipients of

Title XX contracts through the purchase-of-service route. They are assuming that these private agencies generally do not serve the very poorest of persons. They have raised a challenge which agencies such as UCPA must counter. These philosophical conflicts present obstacles to the utilization of public funds for persons with disabilities.

Related to this philosophical conflict, a recent decision paper prepared by the National Association of State Mental Retardation Program Directors (NASMRPD) further concluded:

> "Programs for developmentally disabled persons too often operate on a "last-in, first-out" basis, as funding patterns ebb and flow. In one case cited by a survey respondent, all Social Service funds in her state were channeled through the state's mental health clinics; since the clinics did not serve people with cerebral palsy, their participation in Social Service programs was severely limited during periods of modest funding."

- Federal Policy Vacuum

In preparing a decision paper on utilization of generic federal assistance programs, NASMRPD found the one issue raised repeatedly by individuals associated with developmental disabilities across the nation was the lack of clear set of overarching principles to guide the federal government's efforts to assist persons with developmental disabilities. There is no national policy statement of specifics addressing the needs of persons with developmental disabilities.

The President's Committee on Employment of the Handicapped in its report Housing and Handicapped People concluded that the current prospect for increasing the quantity and improving the quality of housing for adults with disabilities is both promising and uncertain; "Uncertain, because this forward trend lacks a rudder to guide it, namely, a national policy and program to assist states and communities to develop diversified local housing related to the special shelter and service needs of persons with a broad range of handicapping conditions."

This policy vacuum is particularly evident in the federal response to deinstitutionalization. Each federal agency with an actual or potential impact on deinstitutionalization of the developmentally disabled tends to develop its operational policies with limited regard to their impact on ancillary programs operated by other federal and state agencies and with little or no sensitivity to the overall impact of the federal government's efforts at the state and local level.

The General Accounting Office's recent report on deinstitutionalization of the mentally disabled concluded:

> (We found that,) in the absence of a national stategy or management system to implement deinstitutionalization, federal officials responsible for other programs that affect deinstitutionalization generally (1) were not aware of the national goal or had not received instructions on implementation, (2) had not implemented their programs to help achieve the goal, (3) had not undertaken joint efforts directed at deinstitutionalization, or (4) had not monitored or evaluated their programs' impact on deinstitutionalization."

• Built-In Jurisdictional Conflicts

We talk about a comprehensive and coordinated human services delivery system; yet, this is contrary to our philosophical approach to government. Alexander Hamilton and James Madison, in justifying our new constitutional order of federalism, were very distrustful of government and devised separation of powers between local-state-federal units of government and legislative-executive-jurisdictional branches within government. The system is designed to be fragmented.

• Regulatory Confusion

The NASMRPD decision paper further concluded that:

> "Differential interpretations of regulations within various regional area offices causes an unending series of problems for provider agencies. Interpretations of existing federal policies seem to vary over time and between individuals. The high rate of employee turnover appears to aggrevate the problem."

The UCPA Washington office devotes considerable time to researching data for affiliates to counteract inaccurate federal, regional or state office interpretations.

• The Seed Grant Concept

The seed grant concept operates with government supplying a grant to an agency to initiate the start-up or expansion of a program. The government then expects the grantee to find operational support when the initiation stage terminates. UCPA has encountered mixed success with this approach.

Seed grants, such as those given by State Developmental Disabilities agencies, have served as a major incentive to establish and expand services to persons with cerebral palsy throughout the nation. The seed grant concept works: programs can be established, demonstrated to succeed, and then be picked up financially elsewhere.

To present a candid and complete picture, it must be noted that the seed money concept has frequently failed - at the end of a three year DD grant many UCPA affiliates have not found adequate replacement funds and crises of program continuity have occurred.

• Private Sponsorship Activities/Purchase Of Service

Most federal programs are limited financing schemes; they do not provide actual service delivery. This is also generally true of local and state governments; given the history of state-operated institutions for the disabled, this is probably a good trend.

This means that some agency must be prepared to accept responsibility for finding a means of securing services for persons with disabilities. One prominent technique, used successfully by many UCPA affiliates with the Title XX program, is the purchase-of-service arrangement. Under this scheme, public agencies remain ultimately accountable for service delivery, but they purchase a service through contract with a private provider agency. The private agency thus becomes a legal agent of the governmental agency and is accountable for all services provided and funds expended.

• Reimbursement Delays

Increasingly, public financial assistance is delivered by a purchase-of-service contract rather than by a grant; this generally means that funds are reimbursed following an activity rather than granted prior to undertaking the activity. The NASMRPD decision paper concluded:

> "Chronically delinquent reimbursements, resulting from excessive federal and state red tape, cause serious cash flow problems. Borrowing money against accounts receivable adds an interest expense which is usually not covered in federal/state reimbursement rates."

United Cerebral Palsy Associations, Inc. has received large amounts of governmental financial assistance ($48.2 million in 1978); cash flow is a substantial problem when dealing with governmental agencies. We now advise all our affiliates to budget based on a three month delay in payment, even though funding contracts are signed and binding.

• Congressional Appropriations Process

Many of the reimbursement delays and associated uncertainties are directly related to the Congressional appropriations process. Public laws "authorize" ceilings which a program may be funded at if approved by Congress annually. "Appropriating" funds is an annual process for determining the amounts which will actually be spent on programs for a given year. In addition to specifying amounts of money for programs for a given year, Congress, through the appropriations process can earmark or target funds upon particular activities of separate programs. The process is highly political; seven out of the last nine DHEW annual appropriations bills have been vetoed by the President. When the fiscal year ends and there is no signed appropriations law, all agencies must continue business under a "continuing resolution"; this means that agencies may only spend at the limits they spent last year. These federal complications are translated into state and local government budgetary difficulties.

• Open vs Closed Budget Approaches

Roughly 89% ($161.2 billion) of DHEW's proposed fiscal year 1979 budget was devoted to "entitlement programs" referred to as "the uncontrollables" (Social Security benefits, Medicare, Medicaid, AFDC, SSI, etc.). Only 11% ($20.1 million) of DHEW's budget was for discretionary programs. The open budget approach, based on individual entitlement, is being challenged by policy and budget planners.

The Title XX Social Services program utilizes a closed budget approach; Congress has established a $2.5 billion annual ceiling on the program despite individual entitlement for service. Mechanisms to control spiraling costs will increase. Efforts to balance entitlement funding with discretionary programs, such as hospital cost containment, will continue.

• Affirmative Action/Nondiscrimination

Increasingly, the federal government is requiring all recipients of federal funds, and particularly those agencies claiming to serve the disabled, to recruit and place disabled persons in crucial decision-making positions. Three examples will demonstrate:

1) Developmental Disabilities. Section 106 of P.L. 94-103 required that each recipient of federal assistance under the DD program take affirmative action to employ and advance in employment qualified disabled individuals.

2) Section 503 of the Rehabilitation Act requires that any agency in receipt of a federal contract in excess of $2,500 operate an affirmative action program for persons with disabilities.

3) Section 504 of the Rehabilitation Act prohibits any otherwise qualified disabled individual from being denied benefits or subjected to discrimination under any program or activity receiving federal financial assistance.

• Objectives vs Performance

Designers of social legislation in the past decade have concentrated primarily on what ends should be sought. Most federal programs are characterized by (1) a grant-in-aid of funds to state and local governments or private entities, conditional upon the submission and approval of (2) a plan setting forth the objective for which the funds will be used.

But objectives, plans, and budgets are not synonymous with actions and results. Promises are not performance. It is becoming increasingly important to recognize the difference between objectives and plans on the one hand and performance on the other. Public program performance depends upon the behavior of a large number of independent decision-makers, both public and private.

In October and November, 1975, the Gallup Organization conducted a national sample poll to determine the public's attidude toward the disbursement of funds of voluntary health organizations as compared to that of government agencies involved in similar programs. Voluntary organizations were named more efficient more often than government by a ratio of 3 to 1.

In early 1977, a Better Business report quoted a National Association of Life Underwriters study indicating that for every dollar reaching those in need, through federal distribution the cost is $3.00, through voluntary organizations the cost is $0.27, and through the church the cost is $0.08. Governmental performance levels are clearly an issue which must be improved upon if federal funding sources are to become more responsive. President Carter's Civil Service reform plan was one effort to improve governmental performance.

MAJOR FEDERAL PROGRAMS SUPPORTING SERVICE NEEDS OF PERSONS WITH DEVELOPMENTAL DISABILITIES

Workshop participants received two sets of handouts with an oral presentation:

• Excerpts from the Guide To Federal Programs For The Developmentally Disabled published by the Federal Programs Information And Assistance Project (sponsored by the Governmental Activities Offices of EFA, NARC, NSAC, and UCPA).

- Index of UCPA Word From Washington Analysis papers.

RECENT ENACTMENTS OF SIGNIFICANCE OF THE 95TH CONGRESS

Workshop participants received two handouts with an oral presentation:

- Index of 1978-1979 UCPA Word From Washington Analysis papers.
- November/December 1978 Word From Washington newsletter.

POLICY ISSUES OF THE FUTURE IMPACTING UPON PERSONS WITH DEVELOPMENTAL DISABILITIES

- Umbrella Vs Categorical Service Organization

Public administrators have been debating for a decade the classic argument of whether publicly financed human services should be organized and administered through categorical or umbrella agencies. Conventional public administration "wisdom" argues that consolidated or umbrella agencies are efficient and effective units of goverance. From the advocate's perspective, the fundamental issue involves targeting of resources. As the Human Resources Organization Studies Group of the President's Reorganization Project concluded:

> "The primary disadvantage of program consolidation is that some desirable targeting of resources on very specific needs and problems may be lost" (President's Reorganization Project, July, 1978).

Experience has repeatedly demonstrated that low visability groups, such as the disabled and subgroups within the disabled, tend to lose resources unless a specific target to their needs exist. This is the fundamental assumption; umbrella agency proposals do not guarantee a continuation of targeting.

There is a trend toward what some refer to as "the cybernetic state" which has a systemic rather than a functional orientation (Allen Schick, 1971, pages 214-233). Such a system tends to be guided by systems engineers, planners, and other generalists whose perspectives presumably transcend their functional specialities. The emphasis in such a system is on "central-guidance clusters," such as the Council of Economic Advisers and OMB. In theory, mass, class, and individual identities become more important than group associations. Those representing target populations do not feel confident that these system engineers have the understanding, awareness, or sensitivity to adequately plan services for specific target groups. Functionalism may not be as efficient as a systems approach but it is probably more representative. The major reservation about an integrated human service delivery system is that the unique objectives of low visability interest groups within society may tend to receive short shrift in organizational configurations emphasizing efficiency.

What has been the experience of persons with disabilities with umbrella agencies? Several years ago the state of Florida consolidated its Vocational Rehabilitation (VR) program into an umbrella human service agency. A federal audit of the performance of the umbrella agency's rehabilitation of handicapped persons confirms the

advocate assumption. Between 1973 when the Florida VR agency operated as a single state agency categorical program and 1977 after several years umbrella experience, the total number of handicapped people served declined 52%. The auditors concluded that "there is evidence that considerable amounts of VR money also are being diverted" resulting in a suspension of services to 4,154 disabled persons in 1978. As a result of the audit, Florida may have to repay the federal government $2.2 million in federal VR funds which was misspent on other services (David Cook, June 1, 1979). The Florida example demonstrates that handicapped people are not better served by umbrella agencies and that their needs are better respected by categorical programs.

The June, 1978 Human Resources Organization Study contains an excellent statement of the central dilemma: "The desire for a flexible, pluralistic system of service agencies responding to specific client and community needs is difficult to reconcile if not in conflict with the preference for a coordinated and comprehensive service delivery system which can be administered according to a consistent set of goals and by administrative mechanisms broad enough to address the many needs of individuals and families" (President's Reorganization Project, op. cit.).

The debate between categorical and umbrella agency responsibility will continue for years. It will generally be resolved through political considerations. Advocates for persons with disabilities will generally maintain the necessity for a categorical approach.

• The Panacea Of National Health Insurance

For years persons working in the disability field have maintained that all our financing problems will be solved when we enact national health insurance. We have waited a long time and we will continue to wait.

The current emphasis within the Congress is on a catastrophic illness protection schema. S. 350, by Senators Russell Long (LA), Abraham Ribicoff (CT), and Herman Talmadge (GA) and six others, would establish a catastrophic health insurance plan, standardize and federalize the Medicaid program and promote standardization of private health insurance plans. The thrust of S. 350's catastrophic protection is to cover financial burdens for traditional medical services after an individual has incurred a medical bill of $2,000 or spent 60 days in a hospital during a calendar year. Senators Long, Talmadge, and 9 others have also introduced S. 351 which is identical to S. 350 except for the absence of the Medicaid revision. Senator Long has also modified S. 350 with S. 760; benefits are similar but the financing mechanism differs.

The Republican alternative to S. 350 and S. 351 is S. 748, by Senators Robert Dole (KS), Peter Domenici (NM), and John Danforth (MO), which would expand the range of Medicare benefits and numbers of recipients including the addition of catastrophic coverage, require employers to offer a catastrophic health insurance plan to full-time workers, and authorize the federal government to negotiate between insurance companies and uninsured persons in contracting for catastrophic coverage.

The Senate Finance Committee has completed some preliminary consideration of a catastrophic plan. These proposals do not provide a new health insurance program of basic benefits for the disabled. In each proposal Medicare and Medicaid continue to be the basic program for the disabled. Catastrophic proposals are acute illness/medical services/hospitalization oriented.

• Utilizing Medicaid For 24 Hour Residential Services

Since 1971 the legal authority has existed for Medicaid to finance Intermediate Care Facilities for the Mentally Retarded (ICF/MR) and persons with "related condi-

tions" defined as persons with developmental disabilities. Because there is currently no federal ceiling on Medicaid funding, because the federal matching is very reasonable, and because of severe funding limitations within all federally financed service programs, several states have financed small group residences for the developmentally disabled as ICF/MRs.

For example, in Minnesota there are 20 group homes for the mentally retarded for 6 to 10 persons financed as ICF/MRs. The population served in these community-based facilities is similar to those people who remain in the state institutions. Additionally, 250 private community-based programs for the mentally retarded are certified as Medicaid facilities.

There have been reservations expressed by program staff associated with consumer organizations, such as the National Association for Retarded Citizens and UCPA, about the desirability of promoting on a large scale group living arrangements financed completely by the ICF/MR authority.

Those that advocate ICF/MR utilization expansion emphasize several points. One, Medicaid appears to be the most easily available funding resource for residential programs. Two, the states are permitted much flexibility in interpreting Medicaid regulations. Three, the ICF/MR program need not perpetuate the medical model. For example, the requirements for "qualified mental retardation professionals" include backgrounds in the social sciences and education and not necessarily medical or nursing experience.

Those who express reservations about promoting ICF/MR funding emphasize other points of view. One, they maintain that there exists a medical orientation in the ICF/MR program; the authority is contained in the Title XIX "medical services" program. They raise questions such as: Does it maximize independent development? Is programmatic appropriateness determined by funding convenience? Do all residents of ICF/MRs require 24 hour supervision? Two, keeping the Title XX precedent in mind, there is a possibility for Congress to place an arbitrary ceiling on Medicaid's open-endedness. The current Congressional concern with cost-containment reflects this concern. Three, many feel that there are added costs attached to ICF/MR construction. Is it not difficult to avoid an institutional orientation because of licensing and fire safety requirements? It generally takes 2 years to develop and construct an ICF/MR; when compared to utilization of existing housing, should deinstitutionalization be held up this long?

Four, the flexibility granted to the states can be a real problem. In Colorado, anyone admitted to a Title XIX facility is required to remain there for a minimum of one year. Five, there is a tendency in ICF/MRs to associate individuals by commonality of classification whether by diagnosis or function; is this normative? Six, does the federal government have the ability to do a good job of monitoring?

And last, there is the possibility of Congressional restrictions on the use of Medicaid for small group residences, particularly non-medical ones. Under existing law, State Medicaid agencies decide if ICFs are qualified to participate in Title XIX. S. 505 (hospital cost containment) would establish a uniform health care facility certification process for Medicaid and Medicare long-term care facilities. State agencies would continue to survey facilities but HEW would determine a facility's eligibility.

This debate will continue for the immediate future; it will not go away.

A DHEW Task Force On Deinstitutionalization proposed a January 12, 1978 option to promote community-based care by changing the federal matching rates to provide incentives and disincentives for certain types of services. The proposal is based on the following assumption:

> "Medicaid (Title XIX), by virtue of open-ended funding and an average federal match of 56.8%, provides to States a strong incentive toward institutional care of the impoverished chronically ill and disabled. Historically, Medicaid was meant to pay for the care of medical indigents and, as such, cannot be faulted for the medical model that it encompasses. But more powerful than the medical model of care and treatment is its open-ended budget - an irresistable attraction for the States, service providers, and client groups alike. Thus, we have witnessed ballooning growth of the Medicaid budget, accompanied by constant pleas for increased coverage of population and services and for more flexible standards."

The option proposal attempts to limit institutional care while promoting community alternatives. Such an approach would cap the Medicaid budget, increase the Life Safety Code standard requirement, reduce the federal matching rate for institutional services, and increase the federal matching rate for community service programs, specifically for Title XX Social Services, Vocational Rehabilitation, Developmental Disabilities, and Community Mental Health Centers. The proposal utilizes federal matching rates as national policy preferences. If we are serious about deinstitutionalization, why not alter the existing federal matching formulas to promote community living?

• Deinstitutionalization And The Union Backlash

Section 133(b)(29) of P.L. 94-103, the 1975 DD Amendments, mandates the States to provide for fair and equitable arrangements to protect the interests of employees affected by deinstitutionalization. This amendment was strongly advocated by the American Federation Of State, County, And Municipal Employees (AFSCME). At the time many advocates feared that Section 133(b)(29) could become a substantial obstacle to reducing the size of state institution populations and promoting small, dispersed, community-based facilities.

On June 15, 1979 AFSCME filed a formal complaint against the State of Rhode Island and HEW's Developmental Disabilities Office charging inadequate job protection for employees affected by the state's deinstitutionalization plan. Because the complaint was signed by AFSCME International President Jerry Wurf, such a complaint could be filed in other states. The complaint was filed on behalf of 750 employees (75% of the staff) at the Joseph R. Ladd School.

HEW guidelines specify that the states must:

1) Ensure "the preservation of rights, privileges, and benefits (including continuation of pension rights and benefits) under existing collective bargaining agreements;"

2) Ensure "the protection of individual employees against a worsening of their positions with respect to their employment"; and

3) Ensure "maximum efforts be made to guarantee employment of employees..."

AFSCME charges that Rhode Island failed to give AFSCME six months written notice prior to the formation of its deinstitutionalization plan, did not develop its plan consultation with employee representatives, and did not develop specific employee assurances relating to deinstitutionalization activities. Rhode Island has planned to retrain institutional employees and transfer them to newly established community residences. AFSCME maintains that if these failures are not corrected, HEW must withhold DD funds from Rhode Island.

• Independent Living: A Service, A Funding Program, Or A Social Movement?

UCPA affiliates have long been dissatisfied with Vocational Rehabilitation's failure to serve persons with severe handicaps, have developed special support programs for persons excluded from generic service systems because of the severity of their disability, and have advocated for a permanent funding base to finance supportive services which will allow severely disabled persons to live in the community. This advocacy has been an objective of the UCPA Washington office since its establishment in the fall of 1968. The P.L. 95-602 Title VII "Comprehensive Services For Independent Living" program is a response to this advocacy effort.

The IL program is also a response to a new social movement, the movement for independent living. In describing the IL movement, Gerben DeJong focuses on the Center for Independent Living at Berkeley, organized in 1972, and the American Coalition Of Citizens With Disabilities, organized in 1974, as the "real beginnings" of the movement. DeJong views IL as a consumer movement and a social phenomenon characterized by the following philosophies:

1) Consumerism: "Basic to consumerism is a distrust of seller or service provider... With the rise of consumer sovereignty, professional dominance in disability policy and rehabilitation is being challenged."

2) Self-Help: The objective of the "self-help movement" is to "give people the opportunity to exercise control over their own lives and the services they use." This movement is fueled by the same "distrust of professionally dominated services" as consumerism. These proponents view themselves as "an alternative service provider" emphasizing peer counseling and advocacy services which, according to DeJong, are "not provided by mainline human service organizations."

3) Demedicalization: This concept supplements self-help and consumerism by challenging the dominance of medical professionals and furthering self care. It maintains that individuals can and should take greater responsibility for their own health and medical care. To DeJong, once medical stability of a disability has been obtained, "medical presence is both unnecessary and counterproductive... Disabled persons are insisting that the management of their disabilities is primarily a personal matter and only secondarily a medical matter."

DeJong maintains that the IL movement has concentrated its energies on a relatively few major disability groups - those with spinal cord injury, muscular dystrophy, cerebral palsy, multiple sclerosis, and post-polio disablement - and on the older adolescent and younger working age adult. This age focus is a function of the disability conditions emphasized to-date and the communities (large academic settings) where IL has taken root. Consumer sovereignty and self reliance have combined into a movement concerned primarily with civil, political, and economic/benefit rights. To DeJong, "the movement's philosophy not only affects what services are to be provided but also how services are to be provided."

This is yet another issue to be debated for the years to come. What exactly is independent living for the developmentally disabled? How should it be financed? And who will determine its meaning and operation?

• Considering A Federal Long Term Care Program

The U.S. Congressional Budget Office, in defining long-term care as health and social services provided to chronically disabled persons, has estimated total demand for such services to increase from 5.5 to 9.9 million persons in 1975 to 6.3 to 11.1 million persons in 1980. Of these 5.5 to 9.9 million functionally disabled persons, only 1.9 to 2.7 million received long-term care under government programs in 1975. Of importance to UCPA affiliates is the estimate that 1.4 to 4.7 million of these persons are between the ages of 18 and 64. In 1975, federal, state, and local governments spent $5.7 to $5.8 billion on long-term care; $3.1 billion or 56% of this was federal spending and 77% of this funding was derived from Medicaid.

The CBO concluded that "perhaps the single largest factor behind the lack of adequate or appropriate long-term care for a large number of the chronically disabled is the general lack of formal alternatives to institutional care."

The CBO study assumed that there would be little, if any, long-term care benefits in any national health insurance scheme and conceptualized three alternative possible future approaches.

1) Stimulate noninstitutional services under Medicare and Medicaid.

Such a proposal would require home health benefits as a mandatory service. One of the major arguments against this proposal is that the existing federal financing mechanism, while opening up benefits for community care, would continue to promote institutional services.

2) Establish a long-term care insurance entitlement program.

This proposal envisions institutional care, sheltered living and congregate housing, and home based services. The CBO declares that "demand for long-term care services under an entitlement (insurance) program is potentially very large because the estimated need is great." Thus, satisfaction of demand, which would depend on an increase in the supply of services, would not be fulfilled.

3) Consolidate current long-term care financing sources and funnel these through a single agency responsible for long-term care.

This proposal would consolidate long-term care benefits under Medicare and Medicaid with Title XX Social Services into a 60% federal matching grant program. States would be required to establish community centers. This option would provide an administrative focus for long-term care, establish a uniform set of services, and eliminate the divisions between health and social services now necessitated by current financing arrangements. This would not be an entitlement program so the number of people served could be limited by appropriations.

• Can We Afford And Are We Willing To Spend The Necessary Resources?

COMPARISON OF EXISTING PROGRAMS WITH CBO PROPOSALS

(in billions)

	1980	1982
Potential Demand	$ 32-47	$ 42-60
Existing Federal Programs	$ 7-8	$ 9-10
Home Health Expansion	$ 8-9	$ 11-14
Entitlement Program	$ 20-23	$ 29-36
Long-Term Care Grant Program	$ 8-9	$ 11-14

Is society willing to devote $60 billion annually to ensure that all persons with substantial disabilities receive necessary and appropriate services which allows them to reside where they desire?

CONCLUSION

John Ashbaugh and Sue Stoddard have discussed the phenomenon of "great expectations" and its impact on publicly financed services. The nature of consumer expectations are built into legislation; the statutory goals are frequently vague, idealistic, and sometimes contractory. P.L. 94-142 declares that every handicapped child has the right to a free, appropriate, public education. Federal housing laws declare that every American has the right to decent, safe, and secure housing. Legislation may call for many due process protection provisions for consumers or for maximum feasible consumer participation in program design and operation while at the same time exhorting the program to move more consumers through a service at minimum cost. For example, P.L. 93-112 required the Vocational Rehabilitation program to serve the more severely disabled while the program continues to be evaluated for success by the question of how many people were rehabilitated into gainful employment?

Public administrators must then confront the realities of implementing a program. Expectations vs resources and manpower; the administrators define the tradeoffs. Thus, few programs ever reach their ideals as stated in statute. The results are frustrated program performance and consumers, charges of low quality and insensitivity, and loss of confidence in the program, service, and professionals associated with the system.

This discussion is an appropriate conclusion to an orientation to the public service delivery system for persons with developmental disabilities because this presentation is followed by Instructional Course Number 14: Current Federal Legislation Affecting Health Professionals In Developmental Disabilities.

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